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Running head: SLEEP QUALITY AND STRESS

Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities

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Abstract

Objective: This study examined the psychosocial predictors of poor sleep quality in parents caring for children with developmental disabilities.

Methods: Sixty-seven parents of children with developmental disabilities and 42 parents of typically developing children completed the Pittsburgh Sleep Quality Index, and measures of parental stress, child problem behaviors, and social support.

Results: Parents of children with developmental disabilities reported poorer sleep quality. Further, the majority of these parents met the established 'poor sleepers' criterion. The strongest predictor of poor sleep quality was parental stress. This finding withstood adjustment for a number of potential confounders.

Conclusions: Parental stress is associated with poor sleep quality in parents of children with developmental disabilities. The monitoring and management of sleep issues in these parental caregivers should be a priority for health professionals.

Key words: Developmental Disabilities, Behavior Problems, Sleep, Social Support, Stress

Introduction

Sleep quality is an important aspect of well-being and is strongly related to overall quality of life (Zammit, Weiner, Damato, Sillup, & McMillan, 1999), life satisfaction (Paunio et al., 2009), secretion of the stress hormone, cortisol (Spiegel, Leproult, & Van Cauter, 1999), and poorer immunity (Suarez, 2008). However, despite the growing interest in the contribution of sleep quality to the health of those caring for other adults (e.g., McCurry et al., 2007), the relationship between sleep quality and well-being in parents caring for children with developmental disabilities is not well understood (Polimeni, Richdale, & Francis, 2007).

Parents of children with Downs syndrome were found to complain of not getting enough sleep (Hedov, Anneren, & Wikblad, 2002). Further, parents of children with autism have been reported to have poorer sleep quality and more daytime dysfunction compared to controls (Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008; Meltzer, 2008). Elsewhere, between 20% and 45% of parents caring for children with developmental disabilities have been found to report poor sleep quality (Didden, Korzilius, van Aperlo, van Overloop, & de Vries, 2002; Quine, 1991; Robinson & Richdale, 2004). However, the precise mechanisms underlying such associations have yet to be clarified.

Nevertheless, parents caring for children with cystic fibrosis and ventilator-assisted children were characterised by both poor sleep quality and depression (Meltzer & Mindell, 2006), suggesting that distress and disturbed sleep may be interrelated. Caregiving for a child with a developmental disability creates demands much greater than those associated with raising a typically developing child. Indeed, such parents report high levels of parental stress, as a consequence of the substantial emotional, social and personal demands associated with caring (Haveman, Van Berkum, Reijnders, & Heller, 1997; Luescher, Dede, Gitten, Fennell, & Maria, 1999). This increase in caregiving stress may impact on parental sleep quality. In fact, others have found that stress, which was related to children's illness, was associated with sleep patterns in parents caring for children with chronic illness (Meltzer & Moore, 2008). Thus, taken together, it could also be possible that parents of children with developmental disabilities who report higher stress will have poorer sleep quality.

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There is now reasonable consensus that problematic and challenging behaviors are a main source of stress for parents of developmental disabilities (Baker et al., 2003; Blacher & McIntyre, 2006; Floyd & Gallagher, 1997; Hastings, Daley, Burns, & Beck, 2006). Higher scores on the Aberrant Behaviour Checklist (Aman, Singh, & Turbott, 1987) subscales (e.g. lethargy, stereotypical behaviour, and hyperactivity) was associated with greater distress in these parents (Stores, Stores, Fellows, & Buckley, 1998). Similarly, these same behaviors, have been associated with sleep disruptions in developmentally disabled children (Miano et al., 2007; Polimeni et al., 2007), but whether they have consequence for sleep quality in their parents remains to be determined.

Stress among parents caring for children with developmental disabilities has also been shown to vary with social support. Indeed, social support has long been regarded to mitigate distress (Bailey, Wolfe, & Wolfe, 1994; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001) and considerable research has been directed at its role in parents caring for children with developmental disabilities. In comparison to controls, parents of children with developmental disabilities were found to report less social support (Gallagher, Phillips, Oliver, & Carroll, 2008). Social support has generally been found to be inversely related to depression and anxiety in such parents (e.g. Gray & Holden, 1992; Weiss, 2002). Further, in older caregivers of dementia patients poor sleep quality was found to be associated with both social support and negative affect (Brummett et al., 2006). Not only do these studies highlight the existence of different patterns of support between such caregiving parents, they also suggest that sleep quality could vary with levels of social support.

A number of other factors such as caffeine and alcohol intake and cigarette smoking are associated with poor sleep and daytime fatigue (Boutrel & Koob, 2004; Phillips & Danner, 1995). Further, body mass index (BMI) has also been linked to sleep deprivation (Spiegel et al., 1999) with those reporting less sleep having higher levels of obesity (Van Cauter & Knutson, 2008). To our knowledge, though, there are no published studies examining health behaviors and BMI in parents caring for children with developmental disabilities. However, there is evidence that older caregivers at risk of ill-health smoke more, consume more saturated fat, have greater BMIs (Lee, Colditz, Berkman, & Kawachi, 2003) and exercise less

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(Burton, Newsom, Schulz, Hirsch, & German, 1997) than non-caregivers. It could be that some caregivers due to distress or time pressure adopt inappropriate health behaviors which may affect health including sleep quality. Taken together, this evidence suggests that health behaviors and BMI should be considered when examining sleep quality in parents caring for children with developmental disabilities, which previous studies failed to account for. Thus, although the balance of evidence tends to favor the notion that sleep quality is reduced in parents caring for children with developmental disabilities relative to control parents, some methodological problems counsel caution.

As an extension of previous research, (Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008; Meltzer, 2008), the aims of the present study were examine: (1) sleep patterns in parents of children with and without developmental disabilities; (2) the associations between stress, child problem behavior, social support, and sleep quality in parents of children with developmental disabilities; (3) whether unhealthy behaviors, such as smoking, alcohol and caffeine consumption, and BMI account for any such associations. It was hypothesised: first, that parents of children with developmental disabilities would have poorer sleep quality than parents of normally developing children; second, that parents of children with developmental disabilities who reported higher parenting stress, more problem behavior in their children, and low social support would have poorer sleep quality than parents who reported less stress, fewer problem behaviors, and more social support.

Methods

Participants and procedure

Sixty-seven parents of children with developmental disabilities and 42 parents of typically developing children participated in the study. Parents of children with developmental disabilities were recruited via invitation letters distributed by their respective syndrome associations and family support groups. In total, 300 invitation letters were distributed. Inclusion criteria for these parents were: providing home care for a child with Downs, Cornelia de Lange, or Smith-Magenis syndromes, or Autism. The syndrome types were chosen as they represent a wide variety of developmental disability phenotypes. The majority

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of these parents self-reported caring for a child with Autism (55%); the remainder caring for a child with Downs syndrome (33%) and children with other syndromes (12%). Controls were parents caring for typically developing children recruited via local schools and newspaper advertisements. In all, two hundred parents responded to our call for volunteers and each was sent a pack of questionnaires and a prepaid envelope in which to return them. Out of these 200, 109 parents returned the questionnaires, a response rate of 55%. In the parental caregiver group there were eight couples and in the control group five couples (24% of the sample in each case). Parents who did not return the packs invariably cited time pressures and other research commitments as reasons for non-participation. The study was approved by the relevant Research Ethics Committees and all participants gave informed consent.

Measures

Participants' socio-demographics were assessed by standard questions. The Registrar General's social class classification which is based on occupational status was used as a measure of socio-economic status (Office of Population Censuses and Surveys, 1978). Participants were asked to specify the occupation of the head of household, which was scored, 1, professional (e.g. physician), 2, managerial (e.g. director), 3, non-manual/clerical (e.g. secretary), 4, manual (e.g. carpenter), 5, semi-skilled manual, (e.g. bus driver), 6, unskilled manual (e.g. laborer) which was then dichotomized into manual (e.g., carpenter, construction worker)/ non-manual (e.g. physician, teacher), as a measure of socio-economic position.

Sleep quality

The Pittsburgh Sleep Quality Index (PSQI)(Buysse, Reynolds, Monk, Berman, & Kupfer, 1989) is a 19-item self-report questionnaire that assesses sleep quality and sleep disruption. This index encompasses seven dimensions of sleep: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medications, and daytime dysfunction. Scores on items range from 0 (no difficulty), in a particular dimension, to 3 (severe difficulty). For certain items the 0 (not during the past month) to 3 (three or more times a week) scale captures frequency. By summing component scores, a total sleep quality

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score is obtained that ranges from 0 (good sleep quality) to 21 (poor sleep quality). The sum of scores of the seven dimensions yields one global score and clinically, been used to distinguish 'good sleepers' from 'poor sleepers' (Buysse et al., 1989). Further, a global score >5 on the PSQI, resulted in a sensitivity of 98.7 and specificity of 84.4 as a marker for sleep disturbances in insomnia patients versus controls (Backhaus, Junghanns, Broocks, Riemann, & Hohagen, 2002). Thus, this cut-off of >5 of the global PSQI score was also used to distinguish those parents who were 'good sleepers' from 'poor sleepers'. The total scale has acceptable internal consistency (Cronbach's $\alpha = .83$) and good test-retest reliability ($r = .85$) (Buysse et al., 1989). In the present study Cronbach's α for the total scale was .86.

Parental Stress

Parenting stress was assessed using the 20-item family problem subscale of the Questionnaire on Resources and Stress Freidrich Short form (Friedrich, Greenberg, & Crnic, 1983). It has been used extensively in previous studies (e.g. Floyd & Gallagher, 1997; White & Hastings, 2004). In accordance with White and Hastings (2004), the 5-items that measure depression were removed. In this scale parents are asked to respond to statements that have a true/false response format and total scores serve as an index of parental stress. Examples of items include "Taking _____ on vacation spoils pleasure for the whole family." and "I have given up things I have really wanted to do in order to care for _____". This 15-item subscale was found to have a high internal consistency (Kudar-Richardson = .88) (White & Hastings, 2004) and in the present study the Cronbach's α was .92.

Child's problem behavior

The 25-item Strengths and Difficulties Questionnaire (Goodman, 1997) was used to screen for child problem behavior. The measure has five subscales, with one assessing prosocial behavior (e.g. 'kind to younger children') and four assessing problem behavior; emotional symptoms (e.g. 'often unhappy, downhearted or tearful'), conduct disorder (e.g. 'often argumentative with adults'), hyperactivity (e.g. easily distracted, concentration wanders'), and peer relationships (e.g. rather solitary, tends to play alone'). Parents are asked to rate whether

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a behavior is 0, somewhat true, 1, true, or 2, certainly true, of their child with higher scores indicating more problem behavior. Some items are reversed scored (e.g. generally obedient, usually does what adults request). The scale has been shown to be reliable (Cronbach's $\alpha = .76$) and effective at identifying behavioral problems in children (Goodman & Scott, 1999). Further, it has been used extensively in research with children with developmental disabilities (Hastings et al., 2006). Internal consistency for the whole scale in this study was .88. For the purpose of our analyses both total, excluding prosocial behaviors, and problem subscales scores were used.

Social support

Social support was assessed using the 12-item Support Functions Scale (Dunst, Trivette, & Deal, 1988). Parents rated each source of support available to them including practical (e.g. 'someone to help take care of my child') and emotional (e.g. 'someone to talk to about things that worry me') support on a 5-point Likert scale ranging from 1, never, to 5, quite often. The total score was used for analysis, with higher scores indicating more social support. This scale has been shown to be reliable (Cronbach's $\alpha = .86$) and has been used previously in developmental disability research (White & Hastings, 2004). A high internal consistency ($\alpha = .89$) was also evident for the present sample.

Control and confounding variables

Participants self-reported their height and weight for the calculation of their BMI (kg/m²). As in previous research (Gallagher, Phillips, Ferraro, Drayson, & Carroll, 2008; Phillips, Burns, Carroll, Ring, & Drayson, 2005) typical health behaviors were assessed using a questionnaire adapted from the Whitehall II study (Marmot et al., 1991). Participants were asked, on average how much they smoked (0, 1–5, 6–10, 11–20, and 21+ cigarettes per day); how much alcohol they drank (0, 1–5, 6–10, 11–20, 21–40, and 40 + units per week) how many cups of tea/coffee or caffeinated drinks they had each day (0, 1, 2, 3, 4+). A categorical variable was created in each case, i.e., 0 = 1, 1–5 = 2, 6–10 = 3, etc. Participants were also asked how many hours they spent doing exercise activities each week (0, 1–2, 3–5, 6–8 and 8+) the same categorical variable

created, 0 = 1, 1-2 = 2, 3-5 = 3, etc. Further, to control for the influence of child sleep habits on parents sleep quality (Polimeni et al., 2007), parents were asked a single question “Does your child’s sleep patterns keep you awake” which was scored using a simple yes/no format. Similarly, they were asked if their child was on medication to control their behavior, a simple yes/no format, but they were also asked to state the type of medication.

Statistical analyses

Initial analyses of group differences were by Chi-square and univariate ANOVA, with partial eta-squared (η^2_p) as the measure of effect size. ANCOVA was performed to adjust for potential confounding variables. These analyses were employed to test the first hypothesis. Occasional differences in degrees of freedom reflect missing data from uncompleted questionnaires. Subsequent within group analyses were by Mann-Whitney tests and Pearson product-moment correlation followed by multiple linear regression, mainly testing hierarchical models. Bivariate correlations were used to determine whether any of the demographics, health behaviors, stress, child problem behaviors, or social support variables were related to sleep quality. Multiple linear regression analyses were applied to test factors significant in the correlations that were predictive of poor sleep quality in parents of children with developmental disabilities. In the first regressions, psychosocial predictor variables were entered together. This was followed by a second regression where potential confounders such as demographics and health behaviors were tested. A final set of regressions was then conducted, at step 1 potential confounds were entered, followed by predictor variables at step 2.

Results

Group differences in socio-demographic characteristics and health behaviors, psychosocial factors and sleep quality

The parents of children with Downs and other syndromes did not differ from the parents of children on the autistic spectrum on sleep quality or any of the psychosocial factors. Accordingly, parents caring for children with developmental disabilities were treated as a

homogeneous group. The summary characteristics of the two parental groups are presented in Table 1. As can be seen, the groups are well matched on most variables, although parents of children with developmental disabilities were older on average and cared for slightly older children. In terms of health behaviors, control parents had higher alcohol consumption compared to the parental caregivers. Further, there were substantial differences between parental groups on BMI and based on BMI classifications, parents caring for children with developmental disabilities were more likely to be classed as overweight ($BMI \geq 25$) compared to control parents, $\chi^2(1) = 9.23, p = .002$.

[Insert Table 1 about here]

Group differences in psychological predictors and sleep quality

It is evident from Table 2, which reports descriptive statistics and the outcome of unadjusted univariate ANOVAs, that there are substantial differences between the groups on the variables of interest; parents of children with developmental disabilities reported significantly more parenting stress, more child problem behavior (SDQ scores), less social support, and had significantly poorer sleep quality relative to controls. A broadly similar pattern of group differences emerged for the sleep index components; parental caregivers had poorer sleep quality, took longer to get to sleep, spent less time in bed and asleep, had more sleep disturbances and daytime dysfunction compared to control parents. As age of parent and child, alcohol consumption and BMI distinguished between groups, the between group difference in sleep quality was revisited using ANCOVA; the between-group difference in sleep quality withstood adjustment for these potential confounds, $F(5, 97) = 45.56, p < .001$, $\eta^2_p = .320$. Moreover, this η^2_p value signifies a large effect (Cohen, 1988; Pierce, Block, & Agunis, 2004). Further, parents of children with developmental disabilities were more likely to be classed as poor sleepers (> 5 on the sleep index) (Backhaus et al., 2002), $\chi^2(1) = 30.13, p < .001$, compared to parents of typically developing children, 78% vs 22%, respectively.

[Insert Table 2]

Within group analyses

Twenty two percent (n =15) of parents caring for children with developmental disabilities reported that their child was on medication to control sleep and behavior (e.g. melatonin, risperidone, and prozac). However, there was no difference in sleep quality between parents whose children were on medication and parents whose children were not, $Z = 187.50, p = .45$. Age, smoking, caffeine intake, alcohol consumption or child sleep habits were not significantly related to sleep quality. However, there was a positive association between gender, $r = .25, p = .04$, and BMI, $r = .25, p = .04$, such that mothers of children with developmental disabilities and parents who had a higher BMI also had poorer sleep quality. Further, parental stress, $r = .50, p < .001$, SDQ total child problem behavior, $r = .26, p = .03$ were also associated with sleep quality. Parents who reported greater stress or more problem behavior in their children had poorer sleep quality. Analysis of the SDQ subscales, revealed that hyperactive, $r = .27, p = .03$, and conduct, $r = .32, p = .009$, problem behaviors were primarily responsible. The link between social support and sleep quality approached significance, $r = -.23, p = .06$. Moreover, SDQ was negatively associated with social support, such that greater behavior problems were associated with lower social support in parents, $r = -.30, p = .01$; SDQ total was not significantly correlated with parental stress, although the direction was positive for conduct problems, $r = .21, p = .09$. Finally, parents also provided information on whether they had resources (e.g., training) to deal with child problems behaviors, but this was not associated with sleep quality.

Regression analyses were conducted to examine which of the indicated psychosocial variables best predicted poor sleep quality within the parental caregiver group. In competing analyses where stress, SDQ total and social support were entered simultaneously, only stress emerged as a predictor, $\beta = .45, t = 4.17, p < .001$, and accounted for 30% of the variation in sleep quality among these parents. Further regression analyses revealed that gender, $\beta = .25, t = 2.05, p = .04, R^2 = .06$, and BMI, $\beta = .25, t = 2.07, p = .04, R^2 = .06$, were associated with sleep quality. In hierarchical linear model, entering gender and BMI at step 1, and stress at

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step 2, the association between parental stress and sleep quality remained significant, $\beta = .43$, $t = 3.62$, $p < .001$, $\Delta R^2 = .16$.

Discussion

The current study confirmed that parents caring for a child with developmental disabilities report poorer sleep quality (Lopez-Wagner et al., 2008; Meltzer, 2008). This resonates with the wider caregiving literature (Brummett et al., 2006; McCurry, Logsdon, Teri, & Vitiello, 2007; Meltzer & Moore, 2008; Wright, Tancredi, Yundt, & Larin, 2006). Further, the association between parenting stress and sleep quality was still evident even after controlling for a number of potential confounders, such as BMI, which has been associated with poor sleep in numerous studies (Spiegel et al., 1999; Van Cauter & Knutson, 2008). It was also found that in comparison to parents of typically developing children, parents of children with developmental disabilities were more likely meet the criterion for 'poor sleeper' (Backhaus et al., 2002). In fact, 72% of the parental caregivers were 'poor sleepers' compared to 22% of the controls. In a previous study from the US (Meltzer, 2008), 60% of parents of children with autism, compared to 40% of control parents were classed as 'poor sleepers' using the same established cut-off criterion, indicating that our UK sample had, if anything, poorer quality sleep than their US counterparts. When one considers the deleterious health effects attributed to lack of sleep (Paunio et al., 2009; Suarez, 2008; Zammit et al., 1999), the present data highlight the need for close monitoring by health professionals of sleep patterns in these relatively young parental caregivers. In addition, sleep deprivation has been linked to poor daytime functioning and reduced ability to concentrate (Van Dongen, Maislin, Mullington, & Dinges, 2003). The present sample of parental caregivers also reported more daytime fatigue relative to control parents.

The present study also explored whether stress, child problem behaviors or social support were associated with increased risk of poor sleep quality in parental caregivers. Parents of children with developmental disabilities reported more stress and child problem behaviors and less social support, outcomes that are again consistent with the results of previous research (Dunn et al., 2001; Gray & Holden, 1992; Hastings et al., 2006; Weiss, 2002). Previous

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research has also identified associations between child behavioral problems with disruptions in sleep of the children as well as their parents (Miano et al., 2007; Polimeni et al., 2007; Wright et al., 2006). In the present study, child problem behaviors, in particular SDQ conduct and hyperactive problem subscales were mostly associated with poor sleep in the current sample. In addition, our measure of child sleep problems was less than ideal: one item asking parents whether their child's sleep disruption influenced their own sleep. Further, only 36 (54%) caregivers completed this measure, meaning that we had low power to detect effects.

To our knowledge, this is the first study that has tested the relationship between social support and sleep quality in this context. Although it is well recognised that social support mitigates psychological distress (Dunn et al., 2001; Gray & Holden, 1992), its influence on sleep quality is not well researched. This is despite the fact that support in the form of respite care provided by friends and family is frequently employed as a strategy to address sleep issues in some parental caregivers (Wright et al., 2006). Although the observed association between social support and sleep quality did not reach the conventional criteria for statistical significance, it was in the expected direction. This would suggest that the implications of social support for sleep quality are worthy of further study in this context.

In the current analyses, parenting stress emerged as the most robust predictor of poor sleep quality in parents caring for children with developmental disabilities. In fact, when all three predictor variables were entered simultaneously into the regression model, stress was the only factor that emerged as a significant predictor of sleep quality. Further, this association was still evident after controlling for a number of possible confounders, most notably gender and BMI. In other caring contexts (e.g., stroke and dementia) psychological distress was associated with less sleep and increase use of hypnotic medication (Rittman, Hinojosa, & Findley, 2009; Rowe, McCrae, Campbell, Benito, & Cheng, 2008). Others have found that when informal care is demanding and stress-provoking, sleep disturbance in caregivers is greater (Bianchera & Arber, 2007). In addition, stress contingent on offspring illness was found to predict poor sleep in parents of children with physical illnesses (Meltzer & Mindell, 2006). However, it must be acknowledged this relationship could be bi-directional as poor

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maternal sleep was predictive of higher stress and lower mood in mothers of children with typically developing (Meltzer & Mindell, 2007).

A behavioral intervention addressing the daytime challenging behaviors and sleep problems of children with intellectual disabilities was found to improve the stress of parents as well as their sleep (Wiggs & Stores, 2001). The current findings reinforce the importance of using a holistic approach when addressing sleep issues in those caring for a child with a developmental disability. It is likely that whether or not an association emerges between the extent of behavior problems, social support, and sleep depends on which other variables have been included in the analyses. It is possible that behavior problems and social support influence sleep quality largely through parental stress, although behavior problems and stress were not correlated in the present caregivers, but social support and stress were. However, this conclusion should be qualified by our failure to observe significant associations between parental stress and the extent of child problem behaviors. Nevertheless, the correlation between stress and conduct problems was in the expected direction.

The current study has a number of limitations. First, the data are cross-sectional. Accordingly, the poor sleep quality observed in those parents caring for children with developmental disabilities may be transitory. However, there is evidence to suggest that caregiver sleep problems persist over time (Matsuda, Hasebe, Ikehara, Futatsuya, & Akahane, 1997). Second, there is the issue of reverse causation, with poor sleep being responsible for increased stress. However, in other contexts psychological distress has been found to be a powerful predictor of the onset of new caregiver sleep disturbances (McCurry, Gibbons, Logsdon, & al., 2004). Nevertheless, it must be acknowledged that sleep disturbances have been identified as a risk marker for psychological distress (Spira, Friedman, Flint, & Sheikh, 2005), and some have argued that a self-perpetuating spiral of sleep and mood disturbances can develop among caregivers that is often difficult to break (McCurry et al., 2007). Third, women outnumbered men, but this is hardly surprising since they predominate as primary caregivers. Importantly, the ratio of women to men was almost identical in the two parental groups and main results were unchanged after controlling for gender. Fourth, complementing our subjective measurement of sleep quality with objective actigraphic sleep measures would

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have strengthened the study. Fifth, age of parent and child, BMI and health behaviors also differentiated the parent groups. However, the main associations were still evident following adjustment for these variables. Sixth, the lack of information (e.g., socio-demographic, sleep problems) of non-participating parents could also be viewed as a possible limitation.

Relatedly, the present sample was predominantly Caucasian and highly educated; thus our findings may not generalize to other ethnic groups or social classes. Finally, future research could benefit from longitudinal designs to map temporal changes. For example, is the amelioration or exacerbation of stress over time associated with an improvement or a deterioration in sleep quality. Moreover, such designs could incorporate robust measures of child sleep patterns as well as bedtime behaviors, both of which have been found to be associated with parental sleep quality (Meltzer & Mindell, 2007; Polimeni et al., 2007).

In conclusion, compared to parents of typically developing children, parents caring for children with developmental disabilities report poorer sleep quality. Further, the majority of these parents met the established 'poor sleeper' criterion (Backhaus et al., 2002). The strongest and most consistent predictor of poorer sleep quality in parents caring for children with developmental disabilities was parenting stress. Considering that poor sleep quality can have deleterious health consequences, monitoring of sleep quality in these parental caregivers should be a priority for health professionals. Indeed, if unrecognised and untreated, disordered sleep may persist for years, (Benca, 2005; Hohagen, Rink & Kappler et al., 1993).

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References

- Aman, M. G., Singh, N. N., & Turbott, S. H. (1987). Reliability of the aberrant behavior checklist and the effect of variations in instructions. *American Journal of Mental Deficiency*, 92, 237-240.
- Backhaus, J., Junghanns, K., Broocks, A., Riemann, D., & Hohagen, F. (2002). Test-retest reliability and validity of the Pittsburgh sleep quality index in primary insomnia. *Journal of Psychosomatic Research*, 53, 737-740.
- Bailey, D., Wolfe, D. M., & Wolfe, C. R. (1994). With a little help from our friends: Social support as a source of well-being and of coping with stress. *Journal of Sociology and Social Welfare*, 21, 127-152.
- Baker, B. L., McIntyre, L. L., Blacher, J., Crnic, K., Edelbrock, C., & Low, C. (2003). Pre-school children with and without developmental delay: behaviour problems and parenting stress over time. *Journal of Intellectual Disability Research*, 47, 217-230.
- Bianchera, E., & Arber, S. (2007). Caring and sleep disruption among women in Italy *Sociological Research Online*, 12(5), <http://www.socresonline.org.uk/12/15/14.html>.
- Blacher, J., & McIntyre, L. L. (2006). Syndrome specificity and behavioural disorders in young adults with intellectual disability: cultural differences in family impact. *Journal of Intellectual Disability Research*, 50, 184-198.
- Boutrel, B., & Koob, G. F. (2004). What keeps us awake: the neuropharmacology of stimulants and wakefulness-promoting medications. *Sleep*, 27, 1181-1194.
- Brummett, B. H., Babyak, M. A., Segler, I. C., Vitaliano, P. P., Ballard, E. L., Gwyther, L. P., et al. (2006). Associations among perceptions of social support, negative affect, and quality of sleep in caregivers and noncaregivers. *Health Psychology*, 25, 220-225.
- Burton, L. C., Newsom, J. T., Schulz, R., Hirsch, C. H., & German, P. S. (1997). Preventive health behaviors among spousal caregivers. *Preventative Medicine*, 26, 162-169.
- Buysse, D. J., Reynolds, C. F., 3rd, Monk, T. H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh sleep quality index: a new instrument for psychiatric practice and research. *Psychiatry Research*, 28, 193-213.

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Paediatric Psychology* following peer review. The version of record: Gallagher, S., Phillips, A.C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Paediatric Psychology*, 35, 728-737 is available online at: <https://doi.org/10.1093/jpepsy/jsp093>

- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences*, 2nd Eds, Lawrence Erlbaum Associates, Hillsdale.
- Didden, R., Korzilius, H., van Apeplo, B., van Overloop, C., & de Vries, M. (2002). Sleep problems and daytime problem behaviours in children with intellectual disability. *Journal of Intellectual Disability Research*, 46, 537-547.
- Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal*, 37, 39-52.
- Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). *Enabling and Empowering Families: Principles and Guidelines for Practice*. Cambridge, MA: Brookline Books.
- Floyd, F. J., & Gallagher, E. M. (1997). Parental stress, care demands, and use of support services for school-age children with disabilities and behavior problems. *Family Relations*, 46, 359-371.
- Friedrich, W. N., Greenberg, M. T., & Crnic, K. (1983). A short-form of the questionnaire on resources and stress. *American Journal of Mental Deficiency*, 88, 41-48.
- Gallagher, S., Phillips, A. C., Ferraro, A. J., Drayson, M. T., & Carroll, D. (2008). Psychosocial factors are associated with the antibody response to both thymus-dependent and thymus-independent vaccines. *Brain Behavior and Immunity*, 22, 456-460.
- Gallagher, S., Phillips, A. C., Oliver, C., & Carroll, D. (2008). Predictors of psychological morbidity in parents of children with intellectual disabilities. *Journal of Pediatric Psychology*, 33, 1129-1136.
- Goodman, R. (1997). The strengths and difficulties questionnaire: a research note. *Journal of Child Psychology & Psychiatry*, 38, 581-586.
- Goodman, R., & Scott, S. (1999). Comparing the strengths and difficulties questionnaire and the Child Behavior Checklist: is small beautiful? *Journal of Abnormal Child Psychology*, 27, 17-24.
- Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Journal of Intellectual and Developmental Disability* 18, 83-93.
- Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: cross-sectional and longitudinal relationships with behavior problems of

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Paediatric Psychology* following peer review. The version of record: Gallagher, S., Phillips, A.C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Paediatric Psychology*, 35, 728-737 is available online at: <https://doi.org/10.1093/jpepsy/jsp093>

children with intellectual disabilities. *American Journal of Mental Retardation*, 111, 48-61.

Haveman, M., Van Berkum, G., Reijnders, R., & Heller, T. (1997). Differences in service needs, time demands, and caregiving burden among parents of persons with mental retardation across the life cycle. *Family Relations*, 46, 417-425.

Hedov, G., Anneren, G., & Wikblad, K. (2002). Swedish parents of children with Down's syndrome: parental stress and sense of coherence in relation to employment rate and time spent in child care. *Scandinavian Journal of Caring Sciences*, 16, 424-430.

Lee, S., Colditz, G. A., Berkman, L. F., & Kawachi, I. (2003). Caregiving and risk of coronary heart disease in U.S. women: a prospective study. *American Journal of Preventative Medicine*, 24, 113-119.

Lopez-Wagner, M. C., Hoffman, C. D., Sweeney, D. P., Hodge, D., & Gilliam, J. E. (2008). Sleep problems of parents of typically developing children and parents of children with autism. *Journal of Genetic Psychology*, 169, 245-259.

Luescher, J. L., Dede, D. E., Gitten, J. C., Fennell, E., & Maria, B. L. (1999). Parental burden, coping, and family functioning in primary caregivers of children with Joubert syndrome. *Journal of Child Neurology*, 14, 642-648;

Marmot, M. G., Dowey Smith, G., Stansfeld, S., Patel, C., North, F., Head, J., et al. (1991). Health inequalities among British civil servants: the Whitehall II study. *Lancet*, 337, 1387-1393.

Matsuda, O., Hasebe, N., Ikehara, K., Futatsuya, M., & Akahane, N. (1997). Longitudinal study of the mental health of caregivers caring for elderly patients with dementia: effect of institutional placement on mental health. *Psychiatry Clinical Neuroscience*, 51, 289-293.

McCurry, S. M., Gibbons, L. E., Logsdon, R. G., & al., e. (2004). Longitudinal changes in sleep and psychosocial function in Alzheimer's patients and family caregivers. *Sleep Medicine Reviews*, 27, 121.

McCurry, S. M., Logsdon, R. G., Teri, L., & Vitiello, M. V. (2007). Sleep disturbances in caregivers of persons with dementia: Contributing factors and treatment implications. *Sleep Medicine Reviews*, 11, 143-153.

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Paediatric Psychology* following peer review. The version of record: Gallagher, S., Phillips, A.C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Paediatric Psychology*, 35, 728-737 is available online at: <https://doi.org/10.1093/jpepsy/jsp093>

- Meltzer, L. J. (2008). Brief report: sleep in parents of children with autism spectrum disorders. *Journal of Pediatric Psychology*, 33, 380-386.
- Meltzer, L. J., & Mindell, J. A. (2006). Impact of a child's chronic illness on maternal sleep and daytime functioning. *Archives of Internal Medicine*, 166, 1749-1755.
- Meltzer, L. J., & Mindell, J. A. (2007). Relationship between child sleep disturbances and maternal sleep, mood, and parenting stress: a pilot study. *Journal of Family Psychology*, 21, 67-73.
- Meltzer, L. J., & Moore, M. (2008). Sleep disruptions in parents of children and adolescents with chronic illnesses: prevalence, causes, and consequences. *Journal of Pediatric Psychology*, 33, 279-291.
- Miano, S., Bruni, O., Elia, M., Trovato, A., Smerieri, A., Verrillo, E., et al. (2007). Sleep in children with autistic spectrum disorder: a questionnaire and polysomnographic study. *Sleep Medicine*, 9, 64-70.
- Paunio, T., Korhonen, T., Hublin, C., Partinen, M., Kivimäki, M., Koskenvuo, M., et al. (2009). Longitudinal study on poor sleep and life dissatisfaction in a nationwide cohort of twins. *American Journal of Epidemiology*, 169, 206-213.
- Phillips, A. C., Burns, V. E., Carroll, D., Ring, C., & Drayson, M. (2005). The association between life events, social support, and antibody status following thymus-dependent and thymus-independent vaccinations in healthy young adults. *Brain, Behavior, and Immunity*, 19, 325-333.
- Phillips, B. A., & Danner, F. J. (1995). Cigarette smoking and sleep disturbance. *Archives of Internal Medicine*, 155, 734-737.
- Pierce, C. A., Block, R. A., & Aguinis, H. (2004). Cautionary note on reporting eta-squared values from multifactor ANOVA designs. *Educational and Psychological Measurement*, 64, 916-924.
- Polimeni, M., Richdale, A., & Francis, A. (2007). The impact of children's sleep problems on the family and behavioural processes related to their development and maintenance. *E-Journal of Applied Psychology*, 3, 76-85.

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Paediatric Psychology* following peer review. The version of record: Gallagher, S., Phillips, A.C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Paediatric Psychology*, 35, 728-737 is available online at: <https://doi.org/10.1093/jpepsy/jsp093>

Office of Population Censuses and Surveys (1978). *Occupational Mortality 1970–72*. London: HMSO

Quine, L. (1991). Sleep problems in children with mental handicap. *Journal of Mental Deficiency Research*, 35, 269-290.

Rittman, M., Hinojosa, M. S., & Findley, K. (2009). Subjective sleep, burden, depression, and general health among caregivers of veterans poststroke. *Journal of Neuroscience Nursing*, 41, 39-52.

Robinson, A. M., & Richdale, A. L. (2004). Sleep problems in children with an intellectual disability: parental perceptions of sleep problems, and views of treatment effectiveness. *Child Care Health & Development*, 30, 139-150.

Rowe, M. A., McCrae, C. S., Campbell, J. M., Benito, A. P., & Cheng, J. (2008). Sleep pattern differences between older adult dementia caregivers and older adult noncaregivers using objective and subjective measures. *Journal of Clinical Sleep Medicine*, 4, 362-369.

Spiegel, K., Leproult, R., & Van Cauter, E. (1999). Impact of sleep debt on metabolic and endocrine function *Lancet*, 354, 1435-1439.

Spira, A. P., Friedman, L., Flint, A., & Sheikh, J. I. (2005). Interaction of sleep disturbances and anxiety in later life: perspectives and recommendations for future research. *Journal of Geriatric Psychiatry and Neurology*, 18, 109-115.

Stores, R., Stores, G., Fellows, B., & Buckley, S. (1998). Daytime behaviour problems and maternal stress in children with Down's syndrome, their siblings, and non-intellectually disabled and other intellectually disabled peers. *Journal of Intellectual Disability Research*, 42, 228-237.

Suarez, E. C. (2008). Self-reported symptoms of sleep disturbance and inflammation, coagulation, insulin resistance and psychosocial distress: evidence for gender disparity. *Brain Behavior and Immunity*, 22, 960-968.

Van Cauter, E., & Knutson, K. L. (2008). Sleep and the epidemic of obesity in children and adults. *European Journal of Endocrinology*, 159, 59-66.

Van Dongen, H. P., Maislin, G., Mullington, J. M., & Dinges, D. F. (2003). The cumulative cost of additional wakefulness: dose-response effects on neurobehavioral functions and

This is a pre-copyedited, author-produced PDF of an article accepted for publication in *Journal of Paediatric Psychology* following peer review. The version of record: Gallagher, S., Phillips, A.C., & Carroll, D. (2010). Parental stress is associated with poor sleep quality in parents caring for children with developmental disabilities. *Journal of Paediatric Psychology*, 35, 728-737 is available online at: <https://doi.org/10.1093/jpepsy/jsp093>

sleep physiology from chronic sleep restriction and total sleep deprivation. *Sleep*, 26, 117-126.

Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, 6, 115-130.

White, N., & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17, 181-190.

Wiggs, L., & Stores, G. (2001). Behavioural treatment for sleep problems in children with severe intellectual disabilities and daytime challenging behaviour: effect on mothers and fathers. *British Journal of Health Psychology*, 6, 257-269.

Wright, M., Tancredi, A., Yundt, B., & Larin, H. M. (2006). Sleep issues in children with physical disabilities and their families. *Physical & Occupational Therapy in Pediatrics*, 26, 55-72.

Zammit, G. K., Weiner, J., Damato, N., Sillup, G. P., & McMillan, C. A. (1999). Quality of life in people with insomnia. *Sleep*, 22 379-385.

Table 1. Sociodemographic, health behavior and BMI characteristics of each parental group

	Caregivers (n=67)	Controls (n = 42)	Test of difference
Sex (Female)	53 (79%)	30 (71%)	$\chi^2 (1) = 0.46, p = .49$
Marital status (Partnered)	54 (81%)	33 (79%)	$\chi^2 (1) = 0.00, p = .99$
Ethnicity (Caucasian)	60 (90%)	37 (88%)	$\chi^2 (1) = 0.00, p = 1.0$
Occupational status (Professional)	49 (73%)	31 (74%)	$\chi^2 (1) = 0.00, p = 1.0$
Does your child sleep patterns keep you awake (Yes) ^a	24 (68%)	5(39%)	$\chi^2 (1) = 2.08, p = .14$
Mean age of parent (SD) years (range 29-58)	42.7 (6.40)	40.0 (4.77)	$F (1,107) = 5.32, p = .02$
Mean age of cared for child (SD) years (range 3-19)	10.7 (4.16)	8.9 (4.36)	$F (1,10) = 4.17, p = .05$
Cigarettes smoked each day (SD)	1.4 (0.97)	1.3 (0.97)	$F (1,104) = 0.78, p = .78$
Units of alcohol drank each week (SD)	2.1 (1.03)	2.6 (1.08)	$F (1,104) = 5.93, p = .01$
Cups of tea/coffee each day (SD)	2.4 (1.08)	2.4 (1.19)	$F (1,104) = 0.00, p = .96$
Number of hours exercise per week (SD)	2.0 (1.08)	1.9 (1.04)	$F (1,103) = 0.64, p = .24$
Mean BMI score (SD)	27.5 (4.74)	24.7 (4.13)	$F (1,104) = 8.21 p = .005$

^a Forty-nine participants of the total sample (36 caregivers and 13 controls) responded to this question

Table 2. Summary mean psychological and sleep characteristics of each parental group

	Caregivers (n = 67)	Controls (n = 42)	Test of difference	η^2_p
Stress score (SD)	7.3 (3.97)	1.8 (2.79)	F (1,105) = 84.97, $p < .001$.447
SDQ score (SD)	18.6 (6.27)	11.4 (6.06)	F (1,107) = 34.45, $p < .001$.244
Social support (SD)	29.4 (11.39)	37.2 (10.46)	F (1,107) = 12.96, $p < .001$.108
Total sleep quality (SD)	9.9 (3.50)	4.9 (2.02)	F (1,107) = 59.15, $p < .001$.356
Subjective sleep quality (SD)	1.6 (0.96)	0.9 (0.73)	F (1,107) = 15.76, $p < .001$.126
Sleep latency (SD)	1.3 (0.90)	0.7 (0.72)	F (1,107) = 13.93, $p < .001$.115
Sleep duration (SD)	1.6 (1.04)	0.5 (0.67)	F (1,107) = 35.59, $p < .001$.224
Sleep efficiency (SD)	1.7 (1.25)	0.9 (0.98)	F (1,107) = 11.71, $p < .001$.099
Sleep disturbance (SD)	1.2 (0.50)	0.9 (0.34)	F (1,107) = 9.93, $p = .002$.085
Sleep medication (SD)	0.9 (1.09)	0.2 (0.43)	F (1,107) = 17.79, $p < .001$.143
Daytime dysfunction score(SD)	1.5 (0.77)	0.7 (0.44)	F (1,107) = 28.56, $p < .001$.211